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IN THE
Supreme Court of the United States
OCTOBER TERM, 1988

NANCY BETH CRUZAN, by her parents and co-guardians, LESTER L. and JOYCE CRUZAN,
Petitioners,
v.
DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, and ADMINISTRATOR OF THE MISSOURI REHABILITATION CENTER AT MT. VERNON,
Respondents,
v.
THAD C. MCCANSE, Guardian ad litem,
Respondent.

On Petition for Writ of Certiorari to the Missouri Supreme Court

BRIEF OF THE AMERICAN MEDICAL ASSOCIATION, AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS AND MISSOURI STATE MEDICAL ASSOCIATION AS *AMICI CURIAE* IN SUPPORT OF PETITIONERS

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QUESTION PRESENTED

Amici curiae will address the following question:

Whether there is a liberty right under the Constitution of the United States that permits the withdrawal of life-prolonging medical care from a patient who is totally and irreversibly unconscious, when the patient's previous statements and the family's understanding of the patient's wishes demonstrate that the patient, if competent, would choose to forgo life-prolonging medical care.

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INTEREST OF THE *AMICI CURIAE*

Amicus American Medical Association ("AMA") is a private, voluntary, non-profit organization of physicians. The AMA was founded in 1846 to promote the science

and art of medicine and to improve the public health. Its 280,000 members—over half of all physicians currently licensed to practice medicine—practice in all fields of medical specialization.

The AMA's concern in this matter stems from its long-standing role in providing guidance to the medical profession on the ethical demands of medical practice. At the first official meeting of the AMA in 1847, one of the two principal items of business was the establishment of a code of ethics. In the ensuing decades, generations of physicians have worked to refine and reformulate the code as counseled by experience and the temper of the times.

One of the AMA's ethical opinions, Opinion 2.18, App. at 1a, is directly relevant to the matter before this Court. Entitled "Withholding or Withdrawing Life-Prolonging Medical Treatment" and adopted in 1986, Opinion 2.18 confirms that the "social commitment of the physician is to sustain life and relieve suffering." But the Opinion also recognizes that in certain circumstances it is not unethical for a physician to comply with a patient's or surrogate's request to withdraw life-prolonging medical treatment.[1]

The American Association of Neurological Surgeons ("AANS") is a private, voluntary, non-profit, professional association. The AANS was founded in 1931 to promote the advancement of, and the pursuit of excellence in, neurological surgery and related sciences. The AANS

[1] For state supreme court decisions quoting and relying on Opinion 2.18 in circumstances analogous to those presented here, *see In re Grant*, 109 Wash. 2d 545, 747 P.2d 445, 450 (1987) (en banc), *modified in* 757 P.2d 534 (1988); *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674, 684 (1987) (en banc); *In re Gardner*, 534 A.2d 947, 954 (Me. 1987); *In re Peter*, 108 N.J. 365, 529 A.2d 419, 427-28 (1987); *Brophy v. New England Sinai Hospital, Inc.*, 398 Mass. 417, 497 N.E.2d 626, 638 (1986).

represents approximately 3,000 neurosurgeons who practice throughout the United States, Canada and the world.

Neurosurgery finds itself at the center of social change with regard to the deliberate withdrawal of life support systems from patients who are terminally ill. The neurological surgeon is routinely called upon to evaluate injuries to the brain and convey diagnoses and recommendations regarding appropriate medical treatment to patients and their families or guardians.

In May 1987, the AANS issued a position statement, App. at 2a-3a, that is directly relevant to the matter before this Court. Entitled "The Withdrawal of Medical Treatment," the statement recognizes that in certain circumstances it may be appropriate to withdraw life-prolonging medical treatment.

The Missouri State Medical Association ("MSMA") is a private, voluntary, non-profit organization of physicians and medical students. It was founded in 1850 to serve its members through promotion of the science and art of medicine, protection of the health of the public, and betterment of the medical profession in Missouri. The MSMA has 5,500 physician and medical student members, including approximately 80% of physicians in Missouri.

The MSMA's interest in this case stems from its role as a representative of the professional interests of the physicians whose practices are most directly affected by the Missouri Supreme Court's decision. In response to that decision, the MSMA has adopted a resolution, entitled "Right to Forego Life Support," App. at 4a-5a, urging the Missouri legislature to permit the withdrawal of life-prolonging medical treatment in the circumstances present in this case and similar cases.

In developing its positions on the withdrawal of life support, *amici* necessarily struggled with the same profound and troubling issues that are presented for review by petitioners in this Court. The purpose of this brief is

to provide an understanding of the relevant medical facts and a discussion of the reasons why, in the view of *amici*, the legal questions are important and warrant review by this Court.[2]

MEDICAL BACKGROUND

The Persistent Vegetative State

The persistent vegetative state can best be understood as one of the conditions in which patients have suffered a loss of consciousness. Conditions in which there is a loss of consciousness are typically characterized in terms of their duration, brief or sustained, and their degree, partial or total. Plum & Posner, "Disturbances of Consciousness and Arousal," in 2 *Cecil Textbook of Medicine* 2061 (J. Wyngaarden & L. Smith 18th ed. 1988).

There are three major categories of sustained and total loss of consciousness: brain death, coma and the vegetative state.[3] In all three, the cerebral hemispheres, which are responsible for conscious behavior, do not function. Accordingly, the patient has no thoughts, feelings, sensations, desires or emotions. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 174 (1983). There is no purposeful action, social interaction, memory, pain or suffering. *President's Commission* at 174-75, 181. In other words, the patient has lost all awareness of self or the environment. F. Plum & J. Posner, *The Diagnosis of Stupor and Coma* 1 (3d ed. 1982).[4]

[2] Pursuant to Rule 36 of the Rules of this Court, the parties have consented to the filing of this brief. The parties' letters of consent have been filed with the Clerk of the Court.

[3] Syncope (a faint), seizure and concussion are common causes of brief and total impairment of consciousness. *Cecil* at 2073-76. Dementia, on the other hand, is a condition in which there is a partial and sustained loss of consciousness. *Cecil* at 2061.

Brain death, coma and the vegetative state differ in the extent to which there is function of the brainstem, the part of the brain that controls unconscious activity.[5] In brain death, there is a complete and irreversible loss of brainstem function.[6] R. Adams & M. Victor, *Principles of Neurology* 234 (2d ed. 1981). As a consequence, the brain is no longer able to regulate what are known as the body's "vegetative" functions, which include the functions of the heart, lungs, kidneys, and intestinal tract and certain reflex actions. *Stupor and Coma* at 313; *President's Commission* at 175. Mechanical measures or other artificial support can maintain vegetative functions temporarily, but only for a few days or, rarely, for a few weeks after brain death. *Stupor and Coma* at 313.

Patients in a vegetative state, on the other hand, maintain relatively normal brainstem function. Cranford, *The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)*, 18 Hastings Ctr. Rep. 27, 28 (Feb./Mar. 1988). These patients can breathe air, digest food and produce urine without any assistance. *President's Commission* at 175. They experience cycles of sleeping, in which their eyes are closed, and waking, in which their eyes are open. Dougherty, et al., *Hypoxic-Ischemic Brain Injury and the Vegetative State: Clinical*

[4] Other terms have been used to describe brain death, coma and the vegetative state, but they are not widely used. For example, "apallic syndrome" is an alternative characterization of the vegetative state. *Stupor and Coma* at 6. Cerebral death has been used as a synonym for both the vegetative state and brain death. *Stupor and Coma* at 313.

[5] If the brain's structure is analogized to a mushroom, the cerebral hemispheres correspond to the mushroom's cap and the brainstem to the mushroom's stem.

[6] There is also a complete and irreversible loss of cerebral hemisphere function.

and Neuropathologic Correlation, 31 Neurology 991, 992 (1981). Their eyes may move from side to side, seemingly fixating on others in the room, but without maintaining the fixation in any consistent or purposeful manner. *Principles of Neurology* at 233; Cranford, 18 Hastings Ctr. Rep. at 28. They may smile, utter unintelligible sounds, and move their limbs sporadically. Jennett & Plum, *Persistent Vegetative State After Brain Damage*, 1 Lancet 734, 734 (1972). Vegetative state patients also manifest a range of reflex reactions to noxious stimuli; they will grimace, cough, gag and move their limbs. In addition, their pupils constrict in response to light.[7] *President's Commission* at 175; Cranford, 18 Hastings Ctr. Rep. at 28; Levy, Knill-Jones & Plum, *The Vegetative State and Its Prognosis Following Nontraumatic Coma*, 315 Annals N.Y. Acad. Sci. 293, 293 (1978). While all of this activity gives the appearance of consciousness, there is none. These patients, in short, are awake but unaware.

Coma may be viewed as a condition intermediate between brain death and the vegetative state. The brainstem retains some function, but not the range of activity seen in the vegetative state.[8] For example, coma is a sleep-like state in which the eyes remain closed. *Stupor and Coma* at 313. Breathing is impaired and many reflexes are absent. *Principles of Neurology* at 232-33.

Coma and the vegetative state differ also in their duration. Coma rarely lasts more than 2-4 weeks, *Stupor and Coma* at 3, by which time the patient either dies,[9] enters

[7] Thus, while vegetative state patients may *react* to normally painful stimuli, they do not *feel* any pain. Cranford, 18 Hastings Ctr. Rep. at 31.

[8] The extent of brainstem injury in coma varies from one patient to another. *Principles of Neurology* at 232-33.

[9] The majority of patients with a coma that lasts for at least 6 hours do not survive. Levy, et al, *Prognosis in Nontraumatic Coma*, 94 Annals Int. Med. 293, 294-95 (1981); *Cecil* at 2072.

a vegetative state or regains some degree of conscious behavior. The duration of the vegetative state, on the other hand, frequently lasts for more than a few weeks, in which case it may be characterized as a persistent vegetative state. *Stupor and Coma* at 6.[10]

Patients may survive in a persistent vegetative state for several years. In one study, 20% were still alive after one year, *Stupor and Coma* at 345; in another study, 27% were still alive after five years. Higashi, et al., *Five-Year Follow-Up Study of Patients with Persistent Vegetative State*, 44 J. Neurol. Neurosurg. & Psych. 552, 552 (1981).[11]

The persistent vegetative state may be caused by a variety of brain damaging conditions, including head injury, brain tumor, stroke, meningitis or Alzheimer's disease. Higashi, et al., *Epidemiological Studies on Patients with a Persistent Vegetative State*, 40 J. Neurol. Neurosurg. & Psych. 876, 877 (1977). Most vegetative states are preceded by coma.[12] One of the most common causes of the persistent vegetative state is "hypoxia-ischemia": that is, an inadequate delivery of oxygen to the brain by the blood circulation, on account of cardiac arrest, respiratory arrest, carbon monoxide poisoning, hypotensive shock or other derangements.[13] Bates, *Predicting Recov-*

[10] Some experts would not characterize a vegetative state as persistent until it has lasted for a year. Berrol, *Evolution of the Persistent Vegetative State*, 1 J. Head Trauma Rehab. 7, 12 (1986).

[11] Nancy Cruzan is alive six years after her vegetative state began; Karen Quinlan survived for ten years in a persistent vegetative state, L. A. Times, June 12, 1985, § 1, at 4, col. 1, and one patient, Elaine Esposito, died after 37 years in a persistent vegetative state. *President's Commission* at 177 n.16.

[12] On the other hand, a minority of comas evolve into a vegetative state.

[13] There may be inadequate delivery of oxygen to the brain either because the blood carries insufficient oxygen, as in respiratory

ery from Medical Coma, 33 Brit. J. Hosp. Med. 276, 278 (1985). While brainstem cells can survive for 15-20 minutes without oxygen, cells in the cerebral hemispheres can survive for only 4-6 minutes. Cranford & Smith, *Some Critical Distinctions Between Brain Death and the Persistent Vegetative State*, 6 Ethics Sci. & Med. 199, 203 (1979). Consequently, a temporary deprivation of oxygen to the brain may spare the brainstem while seriously damaging the cerebral hemispheres.

The diagnosis of the persistent vegetative state is based on repeated physical examinations of the patient, and can be made with a reasonably high degree of certainty by skilled neurologists, even though there are currently no laboratory studies or tests that unequivocally confirm the diagnosis of a persistent vegetative state. Cranford, 18 Hastings Ctr. Rep. at 29-30. EEGs [14] may show a wide range of abnormality while CAT scans and other scanning techniques cannot distinguish the brain damage in a persistent vegetative state from other conditions of severe damage in which the patient retains somewhat greater degrees of function. Cranford, 18 Hastings Ctr. Rep. at 30.

The prognosis of a patient in a persistent vegetative state depends upon a number of factors, primarily the cause and the duration of the condition.[15] For example, patients, like Nancy Cruzan, whose brain damage resulted from hypoxia-ischemia, do poorly.[16] In one study of

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arrest or carbon monoxide poisoning, or because there is insufficient blood flow to the brain, as in cardiac arrest or hypotensive shock.

[14] EEG is an abbreviation for electroencephalogram. It is a test that measures electrical activity in the brain and may be thought of as the EKG of the brain.

[15] Another important factor is the extent of brainstem function detected in the early time period after the brain injury.

[16] Hypoxia-ischemia is defined, *supra*, p. 7-8.

patients in a coma from hypoxia-ischemia, 23 patients were in a vegetative state after one month. Over the next five months, seventeen died, four remained vegetative and the remaining two improved only slightly. The two who improved were able to utter a rare comprehensible word, but they never responded to commands. Dougherty, et al., 31 Neurology at 997. Similarly, in another study of hypoxic-ischemic coma patients, of the fifteen who were vegetative after one month, none regained independent function. Levy et al., *Predicting Outcome From Hypoxic-Ischemic Coma*, 253 J.A.M.A. 1420, 1423 (1985). Most patients who recover from an hypoxic-ischemic coma do so in fact without entering a vegetative state. Levy, et al., 253 J.A.M.A. at 1422.

The chance of a recovery decreases as the duration of the persistent vegetative state increases. Once a patient has been in a persistent vegetative state for more than three months after hypoxia-ischemia, as Nancy Cruzan has been, "[t]he diagnosis of permanent unconsciousness can usually be made with a high degree of medical certainty. . . ." *Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient*, 39 Neurology 125, 125 (1989).

There have been a few reports of significant recovery after a persistent vegetative state caused by hypoxia-ischemia. In one case, a woman who had been a graduate student began to recover seven weeks after injury and eventually was able to live alone and work as a receptionist. Shuttleworth, *Recovery to Social and Economic Independence From Prolonged Postanoxic Vegetative State*, 33 Neurology 372 (1983). Another patient regained the ability to speak but was unable to read and was limited in his ability to concentrate, remember recent events or learn new information. Rosenberg, et al., *Recovery of Cognition After Prolonged Vegetative State*, 2 Annals Neurol. 167, 168 (1977). See also Snyder, et al., *Delayed*

Recovery From Postanoxic Persistent Vegetative State, 14 Annals Neurol. 152 (1983) (describing patient whose personality returned to normal).[17]

These reports of recovery should be kept in perspective. It is believed that there have been at least 100,000 patients in this country in a persistent vegetative state as a result of hypoxia-ischemia over the past twenty years and there are only three reported recoveries. Moreover, none of those who have recovered from a persistent vegetative state caused by hypoxia-ischemia had been in the persistent vegetative state nearly as long as Nancy Cruzan has been. The latest that recovery has begun is 22 months after the hypoxia-ischemia.[18] Snyder, et al., 14 Annals Neurol. at 152.

Patients whose vegetative state was caused by head trauma have more favorable outcomes than those whose injury was caused by hypoxia-ischemia. In one study, 7% of those in a persistent vegetative state for at least one month after a head injury recovered sufficiently to be classified as "independent, although disabled." B. Jennett & G. Teasdale, *Management of Head Injuries* 311 (1981). Generally under that classification, the disabilities include intellectual deficits, personality changes, speech disorders and partial paralyses. Nevertheless, the patient can work in a sheltered environment and travel on public transportation. Jennett & Bond, *Assessment of Outcome After Severe Brain Damage*, 1 Lancet 480, 483 (1975). Recovery is more common in children than adults. Indeed, the chances of recovery are still significant up until one year after the head injury for patients less than 20 years

[17] There is also a report from Japan of a 26 year old man who began to recover after eight months in a persistent vegetative state. Ultimately, he was able to read a newspaper, add or subtract two-digit numbers and move around in a wheelchair. Higashi, et al., 44 J. Neurol. Neurosurg. & Psych. at 553.

[18] It has been more than six years since Nancy's automobile accident. Pet. Br. at 5.

old. Bricolo, et al., *Prolonged Posttraumatic Unconsciousness*, 52 J. Neurosurg. 625, 632 (1980); Pagni, et al., *Long-Term Results in 62 Cases of Post-Traumatic Complete Apallic Syndrome*, 36 Acta Neurochirurgica 37, 40-41 (1977). See also Alberico, et al., *Outcome After Severe Head Injury*, 67 J. Neurosurg. 648 (1987); Najenson, et al., *Recovery of Communicative Functions After Prolonged Traumatic Coma*, 10 Scand. J. Rehab. Med. 15 (1978).

The possibility of recovery after a long delay is also greater in patients whose persistent vegetative state was caused by a head injury. One patient, who was 18 years old at the time of injury, emerged from her persistent vegetative state 30 months after injury. Arts, et al., *Unexpected Improvement After Prolonged Posttraumatic Vegetative State*, 48 J. Neurol. Neurosurg. & Psych. 1300 (1985). In another case, which was not well documented, six years passed after the injury before the patient's family observed signs of consciousness. Tanhehco & Kaplan, *Physical and Surgical Rehabilitation of Patient After 6-Year Coma*, 63 Arch. Phys. Med. Rehab. 36 (1982).

REASONS FOR GRANTING THE PETITION

For more than a decade since the Karen Quinlan case, *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976), physicians, ethicists, the public and the courts have grappled with the profoundly important questions involved in the medical care of patients who are in a persistent vegetative state with no hope of recovery: May life-sustaining medical treatment be withdrawn? If so, which treatments and under what conditions?

The answers to these questions are particularly critical to the thousands of patients currently in a persistent vegetative state and to the many thousands of family members, physicians and other health professionals who

are caring for them.[19] The answers are also of crucial importance to the public more broadly. They say much about the value our society places on the existence of life and the quality of life. In addition, they are closely intertwined with the general question of treatment for hopelessly ill patients. For perhaps 70% of Americans, a decision will be made whether to provide life-sustaining medical care when devastating illness becomes terminal or irreversible. S. Miles & C. Gomez, *Protocols for Elective Use of Life-Sustaining Treatments* 6 (1989).

Despite the numerous court decisions addressing the withdrawal of medical care from persistent vegetative state patients,[20] those patients, their families and their physicians still do not have sufficient guidance on even the most basic questions. As the Missouri Supreme Court's decision demonstrates, it is not clear whether there is a federal constitutional right for individuals to have medical treatment withdrawn when they are in a persistent vegetative state. Pet. App. at A24-25. Nor is it clear how such a right may be asserted.

I. The Decision Below Conflicts With Principles Of Medical Ethics.

Ethics Opinion 2.18 of the American Medical Association states that it is not unethical in certain circumstances for a physician to comply with the request of a patient or surrogate decisionmaker to discontinue life-prolonging medical treatment, including artificially supplied food and water. App. at 1a. In particular, life-

[19] There are an estimated 5-10,000 patients in a persistent vegetative state. Cranford, 18 Hastings Ctr. Rep. at 31.

[20] See, *e.g.*, *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984); *In re Torres*, 357 N.W.2d 332 (Minn. 1984); *In re P.V.W.*, 424 So.2d 1015 (La. 1982); *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987); *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987) (en banc); *Brophy v. New England Sinai Hospital, Inc.*, 398 Mass. 417, 497 N.E.2d 626 (1986).

prolonging treatment may be withdrawn from a patient in a persistent vegetative state if the patient is *irreversibly* unconscious and the request to withdraw treatment reflects the choice of the patient or the patient's surrogate decisionmaker. App. at 1a. Both of these circumstances were present in this case. Pet. Br. at 5, 6-7.

A right of patients to have all life-sustaining treatment withdrawn in the event of irreversible unconsciousness has been recognized also by a wide range of organization and commissions, including the American Association of Neurological Surgeons and the Missouri State Medical Association,[21] the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,[22] the Hastings Center,[23] and the American Academy of Neurology.[24] In addition, public opinion polls have consistently found that at least 70% of Americans support such a right. *In re Jobes*, 529 A.2d at 446 n.11.

II. The Decision Below Conflicts With Decisions Of Other State Supreme Courts.

Even though a public consensus has emerged, the different state supreme courts have disagreed on the existence of a fundamental right to refuse life-sustaining treatment, particularly the right to refuse food and water that are artificially supplied. In its decision, the Missouri Supreme Court held that the Fourteenth Amendment of the United States Constitution does not provide Nancy Cruzan or her family with the right to discontinue Nancy's medical care. In so holding, the court expressed

[21] App. at 2a-5a.

[22] *President's Commission* at 189-96.

[23] The Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* 26-30, 61 (1987).

[24] *Postion of the American Academy of Neurology*, 39 Neurology at 125.

"grave doubts as to the applicability of privacy rights to decisions to terminate the provision of food and water to an incompetent patient." Pet. App. at A24-25. The court went on to hold that, even assuming the existence of a constitutional right, it would be outweighed by the state's interest in preserving life. Pet. App. at A42-43.

The court's holding sharpens a preexisting conflict among the state supreme courts. Previously, in a case that aiso involved a parent seeking withdrawal of treatment from a patient in a persistent vegetative state, the Washington Supreme Court held that artificial nutrition and hydration could not be discontinued. *Grant*, 747 P.2d at 458-60 (Andersen, J., concurring in part, dissenting in part), *modified in* 757 P.2d 534 (1988).[25]

Three other state supreme courts have permitted withdrawal of nutrition and hydration from patients in a persistent vegetative state. In all three cases, the courts recognized and relied upon a right to refuse medical treatment arising under the federal Constitution as the basis for their decisions. *Brophy*, 497 N.E.2d at 633; *Rasmussen*, 741 P.2d at 681-82; *Jobes*, 529 A.2d at 451, *relying on In re Farrell*, 108 N.J. 335, 529 A.2d 404, 410 (1987).

III. The Decision Below Conflicts With The Decisions Of This Court.

A right to refuse medical treatment follows from this Court's previous opinions. This Court has long recognized that, as part of the "liberty" protected by the Constitution's Due Process Clauses, the Constitution guarantees to each individual certain areas or zones of privacy which remain free from unjustified government interference or intrusion. See *Carey v. Population Serv. Int'l*, 431 U.S. 678, 684 (1977). The essence of the liberty interest denominated as the right to privacy is the concept that an

[25] The court did permit the family to refuse CPR, defibrillation and artificial ventilation. *Grant*, 747 P.2d at 458.

individual in certain circumstances has a right to be let alone, *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting), and that the individual must thus have "independence in making certain kinds of important decisions." *Whalen v. Roe*, 429 U.S. 589, 599-600 (1977). Under this Court's holdings, an individual's decisions become fundamental rights when they have a powerful and perhaps irreversible impact on that person's life. See *Fitzgerald v. Porter Memorial Hospital*, 523 F.2d 716, 719-20 (7th Cir. 1975), *cert. denied*, 425 U.S. 916 (1976):

> It is somewhat unfortunate that claims of this kind tend to be classified as assertions of a right to privacy. . . . These cases do not deal with the individual's interest in protection from unwarranted public attention, comment, or exploitation. They deal, rather, with the individual's right to make certain unusually important decisions that will affect his own, or his family's, destiny.

There are few decisions that have as momentous an impact on a person's destiny as the decision whether to withdraw life-sustaining medical treatment. Even a decision to continue treatment can dictate with specificity the future course of a person's life. For the patient who is irreversibly unconscious, the choice of life means a choice of confinement to a bed, attached to medical machinery, without awareness of self or others. See Rubenfeld, *The Right of Privacy*, 102 Harv. L. Rev. 737, 794-95 (1989). Moreover, the impact on the family's destiny is, in some respects, greater because, unlike the patient, the family members are acutely aware of the circumstances and are called upon to deal with them.

A right to refuse medical care is also supported by the traditional respect this nation has granted to the individual's interest in making personal medical treatment decisions in consultation with a physician. The substantive guarantees afforded by the Due Process Clause encompass

the protection of interests that are "deeply rooted in this Nation's history and tradition." *Moore v. City of East Cleveland*, 431 U.S. 494, 503 (1977) (opinion of Powell, J.).

In deciding whether a particular interest is so embedded, the Court's judgment has historically been informed by whether the interest was protected at common law. *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923). In this regard, it is significant that: "No right is held more sacred, [n]or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person." *Union Pacific Ry. v. Botsford*, 141 U.S. 250, 251 (1891).

Both the common and statutory law of this country have consistently recognized the importance of the individual's interest in being able freely to decide whether to accept care recommended by a physician. This interest is reflected, for example, in the requirement of informed consent to medical treatment. It is for each person to weigh the benefits and burdens of a particular treatment and decide for him or herself whether the treatment is desirable. *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972).

In sum, the Missouri Supreme Court's "grave doubts" as to the existence of a constitutional right to refuse medical care do not appropriately reflect this Court's interpretations of the Due Process Clause.

Even to the extent that the Missouri Supreme Court assumed a right to refuse life-sustaining care, it gave inadequate content to that right. According to the court, any right to have treatment withdrawn would be outweighed by the state's interest in preserving life if continuing treatment would not be excessively burdensome for Nancy. Pet. App. at A36-37, 43. In addition, the court measured the burden solely in terms of the pain and

invasiveness involved in the treatment.[26] Pet. App. at A36-37. However, the court's focus on physical invasiveness overlooks key factors that individuals generally consider in deciding whether to be kept alive in the event of irreversible unconsciousness.

In particular, family members of persistent vegetative state patients are subjected to months, years and even decades of anguish, despair and grief. Many individuals would prefer to spare their parents, spouses and children that kind of emotional burden and the psychological disturbances that often result. Carnwath & Johnson, *Psychiatric Morbidity Among Spouses of Patients With Stroke*, 294 Brit. Med. J. 409 (1987); Livingston, *Families Who Care*, 291 Brit. Med. J. 919 (1985). In addition, there is a profound loss of dignity when a person is unable to maintain even minimal intellectual functioning or physical control and is utterly dependent on medical technology for survival. Finally, many people would choose withdrawal of treatment in the absence of any hope of recovery so that they would be remembered most vividly as they were before becoming persistently vegetative.

IV. The Decision Below Gives Inadequate Recognition To The Role Of The Family.

In many cases, a persistently vegetative patient may have given some indications of his or her treatment preferences before becoming unconscious, without expressing those preferences in a formal legal document. In such cases, according to Ethics Opinion 2.18 of the AMA, the family should ordinarily serve as the patient's surrogate

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[26] Since Nancy could not experience pain and the gastrostomy tube was already in place, the court concluded that there was neither pain nor invasion. Pet. App. at A36. That, however, would be true of any treatment, including artificial ventilation, that was already in place. Consequently, the court's holding also raises serious question whether any medical treatment may be withdrawn from a persistent vegetative state patient.

decisionmaker. See App. at 1a. This is also the view of the American Association of Neurological Surgeons and the Missouri State Medical Association,[27] the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,[28] the Hastings Center,[29] the American Academy of Neurology,[30] and the overwhelming weight of public opinion.[31] It is hardly surprising that people would generally prefer to have family members, rather than judges or legislators, make their treatment decisions for them.

While the other state supreme courts that have decided this issue have generally recognized family members as surrogate decisionmakers,[32] the Missouri Supreme Court expressly rejected a role for the family, or any other guardian, as a surrogate decisionmaker for the persistent vegetative state patient. Pet. App. at A38-42.[33]

The family as surrogate decisionmaker, however, follows directly from the right of an individual to refuse life-

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[27] App. at 2a-5a.

[28] *President's Commission* at 193.

[29] *Guidelines on the Termination of Life-Sustaining Treatment* at 24.

[30] *Position of the American Academy of Neurology*, 39 Neurology at 125.

[31] *Jobes*, 529 A.2d at 446 n.11.

[32] See, e.g., *Jobes*, 529 A.2d at 444-46; *L.H.R.*, 321 S.E.2d at 723; *John F. Kennedy Memorial Hospital, Inc. v. Bludworth*, 452 So.2d 921, 926 (Fla. 1984).

[33] Courts that do recognize family members as surrogate decisionmakers have, of course, conditioned that recognition on specific facts indicating that in the particular case the proposed family member would be an appropriate surrogate. Thus, if there is an indication that the family member would be an unsuitable surrogate, the court may appoint a separate guardian to act as the surrogate decisionmaker. *Jobes*, 529 A.2d at 447. In contrast, the Missouri Supreme Court rejected the use of a family member as a surrogate decisionmaker in all cases.

prolonging medical care. Underlying that right is the principle that the patient's wishes determine the medical treatment provided. And, it is the family members who are generally best suited to determine what the patient would have chosen. Family members have the most intimate understanding of a patient's philosophical, religious and moral views; values about life and the way it should be lived; and attitudes toward sickness, suffering, medical procedures and death. *Jobes*, 529 A.2d at 445 (quoting Newman, *Treatment Refusals for the Critically Ill: Proposed Rules for the Family, the Physician and the State*, III N.Y.L. Sch. Human Rights Annual 45-46 (1985)).

Moreover, family members are generally the most concerned with the patient's welfare. "It is they who provide for the patient's comfort [and] care . . . and they who treat the patient as a person rather than a symbol of a cause." *Jobes*, 529 A.2d at 445. Indeed, the law has historically recognized that the "natural bonds of affection" lead family members to act in the best interests of each other. *Parham v. J.R.*, 442 U.S. 584, 602 (1979).[34]

* * * *

Physicians will always strive vigorously to assist those who want help in their struggle against death. Nevertheless, the reality of modern science is that some patients, though irreversibly unconscious and thus without hope of recovery, can be sustained solely by means of medical treatment and sophisticated technology. For more than a decade, the lower courts have struggled with the ethical dilemmas presented by medical technology that can prolong life for many years in patients who are irreversibly unconscious. Because the governing legal principles are still uncertain, physicians must often refuse to honor

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[34] It would be a simple matter to implement safeguards to protect against situations in which the family does not act in the best interest of the patient. *Jobes*, 529 A.2d at 447. But that inquiry is pretermitted by the broad holding below that no right deserves protection in the face of the state's interest in preserving life.

treatment decisions by patients and their families even though the decisions are fully consistent with principles of medical ethics. *Amici* therefore respectfully request that this Court provide guidance as to the role of the federal Constitution in decisions whether to provide medical treatment to patients who are irreversibly unconscious.

CONCLUSION

The petition for a writ of certiorari should be granted.

Respectfully submitted,

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May 5, 1989

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APPENDIX

APPENDIX

AMERICAN MEDICAL ASSOCIATION

Opinion 2.18 Withholding or Withdrawing Life-Prolonging Medical Treatment.

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the choice of the patient, or his family or legal representative if the patient is incompetent to act in his own behalf, should prevail. In the absence of the patient's choice or an authorized proxy, the physician must act in the best interest of the patient.

For humane reasons, with informed consent, a physician may do what is medically necessary to alleviate severe pain, or cease or omit treatment to permit a terminally ill patient whose death is imminent to die. However, he should not intentionally cause death. In deciding whether the administration of potentially life-prolonging medical treatment is in the best interest of the patient who is incompetent to act in his own behalf, the physician should determine what the possibility is for extending life under humane and comfortable conditions and what are the prior expressed wishes of the patient and attitudes of the family or those who have responsibility for the custody of the patient.

Even if death is not imminent but a patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis and with the concurrence of those who have responsibility for the care of the patient, it is not unethical to discontinue all means of life-prolonging medical treatment.

Life-prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration. In treating a terminally ill or irreversibly comatose patient, the physician should determine whether the benefits of treatment outweigh its burdens. At all times, the dignity of the patient should be maintained.

AANS—POSITION STATEMENT

THE WITHDRAWAL OF MEDICAL TREATMENT

Neurosurgery finds itself at the center of social change with regard to the deliberate withdrawal of support systems from patients who are terminally ill. The following recommendations are presented for consideration in these matters:

1. It is of central importance to have as much certainty in the diagnosis of both terminal illness and irreversible coma as possible. Consultation should be obtained where appropriate and whatever confirmatory tests are necessary to establish the diagnosis should be performed.

2. If the patient is competent, his or her wishes should be honored. If the neurological surgeon cannot in good faith do this, the appropriate course is to find another neurological surgeon to assume the patient's care.

3. If the patient is incompetent, major consideration should be given to what the patient would have wanted or, if that cannot be ascertained, to what the patient's surrogate would have wanted. If the patient's wishes cannot be ascertained, the guiding principle should be what the neurological surgeon feels is best for the patient.

4. The actual decision-making process is best done by the patient's family or surrogate in concert with the neurological surgeon. If there is an institutional group for helping to make such decisions it can be used.

5. "The withdrawal of care" in terminally ill or permanently comatose patients can be used to mean many courses of action. There are situations where institution's legal counsel should be consulted before

any definitive action is taken. The decision-making process, however, should remain between the neurological surgeon and family.

Adopted by the
AANS Board of Directors
May, 1987

6. The AANS Board of Directors adopted a resolution on April 1, 1989 to support the position of the Petitioners in the matter of *NANCY BETH CRUZAN, by her parents and co-guardians, LESTER L. and JOYCE CRUZAN v. ROBERT HARMON, Director of Missouri Department of Health, and DONALD LAMKINS, Administrator of the Missouri Rehabilitation at Mount Vernon.*

MISSOURI STATE MEDICAL ASSOCIATION
HOUSE OF DELEGATES

Resolution #14
(A-89)

Introduced by: Cape Girardeau County Area Medical Society

Subject: *Right to Forego Life Support*

Referred to: Reference Committee on Constitution and Bylaws

WHEREAS, the decision to withdraw *artificial* hydration and/or nutrition (*tube feeding*) from terminally ill or *irreversibly* comatose patients *should be allowed when directed by the patient, family, medical proxy, or by* prior "*Living Will*" declaration of the patient; and

WHEREAS, Section 459.010*(3)* of the "Missouri Declaration on Life Support (Living Will)" prohibits withdrawal of artificial nutrition/hydration and is clearly an infringement upon the rights of the individual by the State of Missouri; and

WHEREAS, many states along with the President's Commission on Biomedical Ethics (1983) have favored "Health Care Surrogate" legislation over "Living Will" laws (459.010-459.030) to preserve patients' right of self-determination when decision making capacity is lost; therefore, be it

RESOLVED, that the Missouri State Medical Association calls upon the Legislature of the State of Missouri to delete *the phrase in* section 459.010*(3)* of the "Missouri Declaration on Life Support" which defines providing *artificial* hydration or nutrition *(tube feeding)* as "not being a death-prolonging procedure"; and be it further

RESOLVED, that the Missouri State Medical Association supports additional legislation which affirms the rights of Missouri citizens to appoint a "Health Care Surrogate". This individual(s) could be chosen by a competent patient to act as his/her medical proxy making health care decisions when patient decision making capacity is lost. Such duly appointed medical proxies should have power to approve or refuse any and all medical treatment, including food and water provided by artificial means (tube feeding), when the burdens of such treatment outweigh the benefits and/or such treatment would violate the wishes of the patient as known by the proxy. Missouri physicians therefore support prompt legislative approval of a Health Care Surrogacy Act or its equivalent to help insure our citizens' right of self-determination; and be it further

RESOLVED, upon passage of satisfactory health care surrogate legislation and deletion of the restrictive phrase in Section 459.010(3), MSMA will support and publicize the value of such legislative changes to Missouri citizens and to physicians and health related professions; and be it further

RESOLVED, that ethical decisions *such as the right to refuse treatment* be left to the individual, *family and/or Health Care Surrogate, and* not to the State.